

# Submission to the Statutory Review of the Data Availability and Transparency (DAT) Act 2022

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*By Prospecion*

**To:** DAT Act Review Secretariat

**From:** Prospecion

**Re:** Statutory Review of the Data Availability and Transparency Act 2022

## 1. Introduction: Unlocking Public Value Through Trusted Health Data Access

Prospecion is an Australian healthcare analytics company with over 12 years of experience partnering with the Department of Health and Aged Care, pharmaceutical companies, and research institutions to improve patient outcomes. We are a perfect example of the many benefits that can flow from responsible access to public data. Our business was built on the foundation of an initial licence to use the PBS 10% dataset through Services Australia. From that starting point, we have grown into a globally recognised analytics company—attracting investment, employing Australians, exporting digital health services, and bringing innovation to the life sciences sector.

We've since developed cloud-based, longitudinal patient-level analytics platforms that support real-world evidence generation, treatment access planning, and prescriber education across Australia, Japan, the US, and other markets.

This progress has been made possible through secure, ethical use of public health data, supported by:

- ISO27001-certified systems
- The Five Safes Framework
- Regular and timely data updates as part of the data supply agreement

Despite this success, there is so much more that could be done. In our experience working internationally, we've seen Australia shift from being a global leader in responsible access to public datasets to now lagging behind countries such as the UK and Canada. The constraints embedded in the implementation of the DAT Act have likely contributed to this decline—by excluding capable private entities, delaying access, and preventing scalable solutions that match the pace of health system needs.

This concern is echoed in the CSIRO's Future of Health report, which highlights that while digital data and analytics are key enablers of an integrated, personalised, and preventative healthcare system, Australia's progress is hindered by fragmented governance, siloed access, and lack of trust and infrastructure to support secure data sharing and value creation.

## **2. A Bottlenecked System: High Demand, Limited Supply, Slow Processes**

Demand for timely, high-quality public data continues to rise across government, research, and industry. But capacity to supply and analyse that data remains limited.

- Public agencies face resource constraints and rising demand, creating bottlenecks.
- Processes remain slow, inconsistent, and opaque, often taking months to progress.
- All access must occur project-by-project, even for routine, repeatable public interest use cases.

The result is significant under-utilisation of national data assets. Opening access to responsible, accredited private-sector entities like Prospection would build capacity without compromising governance. This is not a call for deregulation, but for shared responsibility in delivering ethical and impactful data use.

## **3. A Programmatic Path Forward: From Projects to Purpose**

The DAT Scheme's current project-by-project model is inefficient, particularly for repeatable, high-value use cases such as health equity analysis, treatment adherence, or care pathway benchmarking.

We propose a shift to a programmatic model of access:

- Pre-approved use cases aligned with public value can be governed as a group
- Accredited analytics providers—including eligible private entities—can be authorised under a structured framework
- Reusable governance structures (e.g. standardised ethics review, Five Safes implementation) can accelerate safe access

Such a model exists in international comparators (e.g. ICES in Canada, NHS Digital in the UK) and has demonstrably increased the value derived from public sector data.

## 4. Linked National Health Datasets: An Untapped Asset

Australia is actively building some of the world's most promising linked health datasets—such as those developed by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), and Services Australia. These assets have the potential to transform public health, access planning, and system performance.

Yet they remain largely inaccessible to expert analytics organisations outside government and academia, despite safeguards, governance frameworks, and demonstrated capability.

Responsible access to these linked datasets would:

- Enable earlier identification of access gaps and unmet need
- Accelerate innovation in patient access and education programs
- Inform more accurate health technology assessments and policy design

Without reform, the DAT Act will continue to act as a barrier to the very use cases it was designed to support.

## 5. Delays Are Costing Lives, Innovation, and Investment

Australia's data access environment is not keeping pace with the needs of a modern, data-enabled health system. While progress is being made on the development of linked datasets, these valuable national assets remain underutilised due to restricted access, slow processes, and the exclusion of capable partners.

The consequences are clear:

- Pharmaceutical and medtech companies increasingly deprioritise Australia for real-world evidence generation and early market engagement, citing the difficulty of accessing linked and representative datasets.
- Investments in clinician education, patient access programs, and innovation pilots are being diverted to international jurisdictions that provide faster and more transparent pathways to data use.
- Patients miss out on timely interventions and support, particularly in areas of high unmet need such as rare diseases, complex multimorbidity, and regional or disadvantaged populations.

These impacts are not the result of a lack of data—but of inaccessible and inconsistently governed data systems. The DAT Act, in its current implementation, does not provide a scalable solution to meet this challenge.

To unlock the full value of Australia's linked healthcare datasets, the DAT Scheme must evolve to:

- Enable timely, governed access to high-value datasets
- Implement a programmatic governance model with pre-approved use cases
- Accredited capable, trusted organisations—public and private—to deliver ethical, secure, and impactful analysis at scale

Australia has the opportunity to lead globally in digital health, real-world evidence, and data-driven policymaking. But without action, we risk falling further behind.

## 6. International Models Show It's Possible

Globally, private-sector access to public data is already being enabled under strong public interest safeguards.

- UK (NHS Digital): Allows private organisations to access de-identified data for approved public-benefit research, including patient access and treatment pathway studies.
- Canada (ICES): Partners with trusted private firms under strict governance and ethics requirements, using linked EMR, hospital, and prescription data to improve policy and patient outcomes.

These models demonstrate that trusted access is not only possible—it is beneficial when governed properly.

## 7. Australia Is Ready

Australia has the tools to do this responsibly. Key enablers include:

- Strong legislative and regulatory oversight (e.g. Privacy Act, OAIC)
- Existing governance review frameworks (e.g. EREC)
- Proven domestic organisations with deep experience in de-identified patient data, including across Japan, the US, and Australia

What's needed is a modernised framework under the DAT Act that recognises and governs this capacity.

## 8. Recommendations

We respectfully recommend the following:

1. Retain the DAT Act beyond its 2027 sunset date, to preserve and strengthen Australia's national data sharing infrastructure.

2. Amend the Act to enable accredited private-sector access, subject to:
  - A clear public interest test
  - Mandatory independent ethics review
  - Transparent audit, reporting, and use register
  - Capability-based accreditation including governance, security, and track record
3. Shift to a programmatic governance model, with:
  - Pre-approved, repeatable use cases
  - Reusable governance protocols
  - Defined service-level expectations and efficient approval timelines
4. Pilot this model with a limited group of accredited entities, including capable private organisations using public datasets—such as Prospection—to deliver clearly defined, public-benefit health analytics projects.
5. Establish a cross-sector advisory group to oversee implementation, ensure public trust, and support transparency.

## **9. Conclusion: From Framework to Function**

The DAT Act has strong foundations but needs reform to fulfil its original intent. With modest but important changes—particularly around private-sector inclusion, programmatic access, and process efficiency—Australia can unlock the true value of its data assets for better health, stronger policy, and a globally competitive digital health economy.

We stand ready to contribute to this goal.